



State of Connecticut
Department of Developmental Services



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**DEPARTMENT OF DEVELOPMENTAL SERVICES TESTIMONY
BEFORE THE LEGISLATIVE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE**

February 27, 2015

Senator Fonfara, Representative Carpino, Senator Kissel, Representative Mushinsky and members of the Legislative Program Review and Investigations Committee. I am Jennifer Bogin, Director of the Department of Developmental Services' (DDS) Division of Autism Spectrum Disorder Services. Thank you for the opportunity to testify on **[H.B. No. 6737](#) AN ACT IMPLEMENTING THE RECOMMENDATIONS OF THE PROGRAM REVIEW AND INVESTIGATIONS COMMITTEE CONCERNING TRANSITIONAL SERVICES FOR YOUTH AND YOUNG ADULTS WITH AUTISM SPECTRUM DISORDER**. On behalf of Commissioner Morna A. Murray, I would like to thank the Committee for the time and effort that has gone into studying this important issue that impacts many individuals who are supported by the Department of Developmental Services (DDS) and their families.

Section 5 of **[H.B. No. 6737](#)** has several reporting requirements to which DDS offers the following comments:

(1) The number and ages of persons with autism spectrum disorder who are served by state agencies; *Currently, DDS only has access to information about individuals who are eligible for DDS services including individuals with and without intellectual disability who have an indication of autism spectrum disorder (ASD) on their Level of Need (LON) assessment. It is important to note that an indication of ASD on the LON is not necessarily representative of an actual clinical diagnosis of ASD. Similarly, a LON may indicate that an individual does not have ASD when in fact they do. This is because the 'primary' diagnosis may be listed as intellectual disability when the individual also has ASD. Also, it may not be reflected in an individual's LON that they have an ASD diagnosis if intellectual disability was the primary diagnosis at eligibility. However, the LON indicator provides DDS with a good estimate. It is not clear if other state agencies track information about individuals' diagnoses for those who receive those state agencies' services or programs or what legal authority they have to request this information from applicants. We would caution mandating this reporting requirement of DDS without exploring any legal barriers or cost implications associated with this data collection.*

(2) The number and ages of persons with autism spectrum disorder on the department's wait list for waiver services; *DDS already tracks this information. As of February 26, 2015, there were 543 individuals on the Division of Autism Spectrum Disorder Services (the Division's) Waiver Waiting List.*

(3) The type of waiver services currently provided by the department to persons with autism spectrum disorder; *To clarify, individuals with ASD who have intellectual disability might be receiving waiver or other services from DDS outside of the Division. It is unclear if the committee also is interested in this information, but if so, it could be provided. Individuals who receive services from the Home and Community-Based Services (HCBS) waiver for persons with autism may receive: Community Companion Homes (formerly Community Training Homes); Live-in Companion; Respite; Assistive Technology; Clinical Behavioral Supports; Community Mentor; Individual Goods and Services; Interpreter; Job Coaching; Life Skills Coach; Non-Medical Transportation; Personal Emergency Response System; Social Skills Group; and Specialized Driving Assessment.*

(4) A description of the unmet needs of persons with autism spectrum disorder; *DDS will be able to collect this information with a survey that is being developed for individuals already eligible for services by the Division. The information could be collected going forward for individuals on the Division's Waiver Waiting List for the HCBS waiver for persons with autism, but it would not capture or reflect the needs of individuals not eligible for DDS services or individuals with intellectual disability and ASD who are eligible for DDS services. LON assessments and designation of priority on the DDS Waiting and Planning Lists may provide some of this information more generally. If the committee is interested in information beyond those eligible for the Division, DDS could explore options for data collection with other state agencies that provide services to individuals with ASD.*

(5) The projected estimates for a five-year period of the costs to the state due to such unmet needs; *In the past, DDS has provided and can continue to provide cost projections for the Division's Waiver Waiting List (using estimates based on the waiver cap of \$60,000 and an average cost of services that is currently approximately \$43,500 for children under 21 and \$24,000 for adults). The cost estimates are limited though to the needs of individuals who are eligible for DDS services with ASD who do not have intellectual disability and do not reflect needs of individuals with ASD who receive services or supports from other state agencies. DDS does maintain Residential Waiting and Planning Lists for individuals with intellectual disability, who may also have ASD. This information is available in the quarterly Management Information Report (MIR) produced by the department. Associated costs would be determined by level of need.*

(6) Measurable outcome data for persons with autism spectrum disorder, including, but not limited to, (A) the number of such persons who are enrolled in postsecondary education, (B) the employment status of such persons, and (C) a description of such persons' living arrangements; *The Division keeps track of the post-secondary education and employment status information for individuals currently receiving services from the HCBS waiver for persons with autism and reports it quarterly in the department's MIR. As of December 2014, 37 participants were employed, 25 had volunteer positions and 11 were enrolled in higher education programs. Regarding the living arrangements of individuals; 26 live in their own home, 42 live in a family home, and one lives in another type of residential setting. The Division will continue to track this information for individuals enrolled on the Home and Community Based Supports Waiver for Persons with autism and has plans to begin tracking this information through the previously mentioned survey for individuals on the Division's Waiver Waiting List.*

(7) A description of new initiatives and proposals for new initiatives that are under consideration. *The Autism Spectrum Disorder Advisory Council (ASDAC) plays a key role in making recommendations to the DSD Commissioner for new initiatives after careful discussion, identification and prioritization of key issues related to ASD. Currently, ASDAC subcommittees, at the recommendation of the 2013 Autism Feasibility Study, have proposed activities that are being implemented in the areas of 1) training for teachers and clinicians; 2) creating a comprehensive web-based resource guide; 3) increasing social and recreational activities throughout the state; and 4) developing specialized inpatient beds.*

Also, DDS would like to take this opportunity to mention that on January 1, 2015, Connecticut began implementing a recent directive from the federal Centers for Medicare and Medicaid Services (CMS) for Medicaid coverage of ASD services. These services are available to children under the age of 21 who are eligible for Medicaid. Services may include intensive behavioral support and teaching using Applied Behavioral Analysis. Many children with ASD, but specifically transition age youth, can benefit greatly from these services as they can increase much needed life skills (i.e. cooking, managing money) as well as decreasing challenging or unwanted behaviors. Medicaid will also cover Care Coordination and Peer Navigator services through the Connecticut Behavioral Health Partnership. These services will also be of great assistance to transition age youth. Difficulty navigating the service system is a common theme throughout the LPRIC study report, and case coordinator services will assist in smoother transitions between systems (i.e. school and DDS) as well as give parents a place to call when they are having trouble.

Thank you again for your Committee's and the staff's work on these important issues that impact so many individuals supported by DDS. I would be happy to answer any questions that you may have for me at this time, or you may contact Christine Pollio Cooney, DDS Director of Legislative and Executive Affairs at (860) 418-6066 for additional information.